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Decisions making concerning life-sustaining treatment in paediatric nephrology: professionals' experiences and values

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Running title: ethical reflections on life-sustaining treatments in paediatric nephrology

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Abstract

Background. In a previous paper, we studied decisions to withhold or withdraw life-sustaining treatment (LST) taken between 1995 and 2001 in 31 French-speaking paediatric nephrology centres. Files were available for 18 of the 31 centres. A grid was used to analyse the criteria on which decisions were based, and the results were enriched by an analysis of interviews with the doctors in at these centres (31 interviews with doctors from the 18 centres). The goal was to describe in detail and to specify the criteria on which decisions to withhold or withdraw LST were based, extracted from the files.

The second paper deals exclusively with the interviews with doctors and analyses their lifetime's experience and perception

Methods. We carried out semi-directed interviews with nephrologists from all the paediatric nephrology centres in France and the French-speaking regions of Switzerland and Belgium.

Results. We interviewed 46 paediatric nephrologists. Most were aware that decisions relating to LST are necessary and based on the assessment of the child's quality of life. According to them, decisions are not based on scientific criteria, but on the capacity to accept handicap, the family's past experiences and the doctor's own projections. They report that their task is particularly difficult when their action may contribute to death (withdrawal of treatment, acceleration of the process). They feel that their duty is to help the families in the acceptance of the doctors' decision rather than to encourage their participation in the decision-making process.

Conclusions. This paper shows that paediatric nephrologists differ in their opinions, mostly due to their own ethical convictions. This observation highlights the need to establish common rules taking into account the views held by doctors. This is the only way to establish an ethical code shared by professionals.

Key words: dialysis; ethics; life-sustaining treatments; nephrology; paediatrics; treatment withholding or withdrawal

Introduction

There is a need for guidelines concerning decisions to withhold or to withdraw life-sustaining treatment (LST) and for the adaptation of these guidelines to the medical field and population concerned: adults [1] and children [2-3].

In a previous article [4], we studied the criteria used for LST decisions and identified positive criteria in favour of the continuation of care (isolated renal insufficiency occurring outside the neonatal period, child well integrated in the family or an adapted social structure) and negative criteria favouring decisions to withdraw treatment (neonatal renal insufficiency, incurable extrarenal disease, severe neurological handicap affecting relationships, impossibility of providing social help or finding an adapted care centre after extensive research by a social assistant with expertise in the field). We also highlighted the complexity of such decisions and the need for parents and the paramedical team to participate in the decision-making process. This work, together with that of the French Society of Paediatricians (SFNP), aims to contribute to the establishment of guidelines made for and by the professionals themselves.

The law was changed in April 22nd 2005, making it all the more important to lay down guidelines, as decisions to limit or to withhold treatment have been decriminalised for treatments maintaining life in conditions judged unreasonable. The new law also states that the family must be notified. Transparency is obligatory, because all decisions must be recorded in the patient's medical file [5].

In this article, we consider the opinions of doctors and identify elements of ethical tension that must be resolved by professionals if we are to develop appropriate guidelines.

Methods

This study was designed jointly by experts from the SFNP and from the Medical Ethics Laboratory.

University hospitals are the only centres in France with paediatric nephrology departments. The heads of all these departments were contacted. We also contacted all other French-speaking university hospitals in Europe using the same medical practices in a similarly organised hospital environment.

All 31 French-speaking paediatric nephrology centres were included: 25 in France, two in Switzerland, three in Belgium and one in Luxembourg.

The study was carried out by an investing doctor during 2001. We contacted all the 50 doctors holding permanent positions in the 31 centers and carried out semi-directed, face to-face interviews with those accepted. These interviews were recorded anonymously, with the doctor's consent in accordance with the conditions of the medical secrecy act. The questions asked are listed in table 1. We collected the following data concerning the doctor: age, sex.

Analysis of results

The interviews were analysed double-blind, by two evaluators, using an analysis grid. These two evaluators met to discuss their results, with the aim of reaching a consensus in cases of disagreement. Several answers could be given to questions and the data are expressed as their number of occurrence in the interviews. The ideas, even those rarely expressed, were recorded according to their relevance and ethical impact.

The data from interviews and medical files were analysed with Excel and Statistica. The results are expressed as absolute values and as percentages, and comparisons were made using the Chi² test ($p < 0.05$).

Results

Description of the paediatricians interviewed

We contacted all the 50 doctors holding permanent positions. There were 1 to 4 paediatricians per centre. Four refused to be interviewed, giving a total of 46 interviews.

Thirty men and 16 women participated. Their mean age was 50.4 years (range: 33 to 68 years).

No significant difference was found in the responses given by doctors of different ages and sexes.

In response to the question 1 “Have you ever decided to withdraw or to withhold life-sustaining treatment from a child in nephrologic paediatrics? If yes, was this decision taken in the last five years?” 45 doctors responded “yes” and 31 stated that the decision concerned had been taken in the last five years. We analysed the criteria on which these decisions were based in a previous article [4]. Fourteen doctors had decided to withhold or to withdraw LST from a patient more than five years ago and one doctor had never taken such a decision.

Opinions of paediatricians concerning the withdrawal/withholding of LST

In response to the question 2: “*In your opinion, do you think it is sometimes necessary to withdraw or to withhold LST?*”, 97.8% of the paediatricians (n=45) answered “yes.” The reasons given were: to avoid a future poor quality of life, notably when diminished mental capacities are evident and when no improvement can be expected (n=26), to avoid the artificial prolongation of life by medical means (n=22), to limit suffering in children when there is no hope of improvement (n=13), to protect the family because the treatment is particularly burdensome and requires high level of participation on their behalf (n=13).

One centre does not make decisions to withhold or to withdrawal LST because the two senior doctors are opposed to such practices:

- The head of the department had been deeply moved by an experience of LST withdrawal: “*It was a three-month-old child with oxalosis and renal insufficiency; due to the absence of validated treatment, we decided to stop peritoneal dialysis in this child, who smiled at us when we walked into the room. It was unbearable! I still think about it 15 years later and it is clear that we would not make such a decision nowadays.*”
- His colleague felt that decisions concerning LST in paediatric nephrology are not necessary because of improvements in technology. Furthermore, for him, doctors have no right to decide

whether another person should live or die, *“To be totally honest, I know that LST decisions exists; personally I do not agree with them because I think that—calls up a vision of humanity that is a vision of perfection.”* Unlike most of his colleagues, he stressed that deteriorations in mental capacities should not be a criterion. He explained: *“Why shouldn’t I respect Down’s syndrome patients with an IQ of 80 and who have finally shown in recent years that they can integrate into society? And why would I place my limit at 60 or 20 when our societies are sufficiently rich and structured to care for these children?”* Finally, he said, *“Even the most severely disabled children are capable of affective relationship; they look into your eyes, they are used to being with people, they know who looks after them.”*

When asked *“How important are non-scientific and scientific elements in the decision making process of deciding to withhold/withdraw treatment?”* (question 3), doctors replied that the decisions were based on non-scientific arguments (n=26), both scientific and non-scientific arguments (n=6) and solely on scientific arguments (n=13).

In response to the question 4: *“Which non-scientific and scientific elements do you feel are important?”* the following elements for the non-scientific elements were cited: acceptance of handicap by the doctor (n=14), the parents’ attitude (n=12), the doctor’s ability to see the child as a relative (n=11), the doctor’s interpretation of the results (n=7), the experience of similar cases (n=7), the attachment of the doctor to the child and his or her family (n=7) and the suffering of the child (n=1). The following scientific elements were cited: hopes for future therapies based on current research (n=20), a comparison with similar published cases to get an idea of the prognosis (n=15), the doctor’s experience of similar cases (n=8), the results of biological and radiological investigations (n=7) and the child’s response to the treatments initiated (n=2).

The answers to the question 5 *“Does fear of medical and legal complications affect your decisions?”* showed that fear of such complications had little or no effect (n=37, i.e. 82.2%), or a moderate or notable effect (n=6 i.e. 13.3%). Two doctors did not reply.

Differences between withholding and withdrawing LST

In response to the question 6 “*Do you deal with treatment withdrawal and treatment withholding in the same way?*” only 1 doctor replied that the situations are identical. The 44 others answered that withdrawing LST is more difficult (n=42) because of the responsibility in provoking or accelerating death. The doctor has to deal with psychological pain (n=8) or feelings of guilt (n=8). Withholding LST is less difficult to handle because “we let nature take its course” (n=21) and because the family is informed whereas, in cases of withdrawal, the family is not systematically informed (n=2). Withholding LST was considered more difficult by 2 doctors because the time between making the decision and the child’s death is prolonged.

Ten doctors stated that they are opposed to withdrawal thus had never practiced it.

Eighteen doctors highlighted a real problem: in cases of withdrawal LST, the parents are unlikely to be informed or involved in the decision-making process (DMP) .

Role of relatives in DMP

The answers to the question 7: “*What type of information do you give to parents concerning the discussion about LST decisions?*” showed that the parents were given information about the prognosis and the future of their child (n=36), informed that there was no possible treatment (n=14), told about their child’s comfort and suffering (n=12). In 5 cases, the doctors said that the information given differs according to the family.

The answers to this question uncovered three types of doctor-parent relations: progressive persuasion of the parents by the doctor to convince them that his or her decision is correct (n=27), informing the parents as objectively as possible and allowing them to make the choice (n=10), assessing the parents’ opinion as best possible and deciding in their place (n=8).

Discussion

According to this work, three components appear essential in the DMP: the doctors' moral, religious and ethical background, the doctor-parent relationship and the distinction between an active or passive attitude.

The doctors' background

Our results highlight the ethical tension between professionals — who, in interviews, said that their decisions in such situations were taken on a case-by-case basis, according to their own moral conscience — and society, which is demanding greater transparency, as shown by the new laws [5-7].

Decisions are essentially based on the personal background of the doctors and on their professional experience — whether they are used to evaluating prognosis and their ability to deal with the family [8]. For 60% of the paediatricians interviewed, decisions are based on non-scientific arguments, mainly predicted quality of life. These arguments include acceptance of the degree of handicap within the family and within society, as highlighted by other studies [8-9].”

In our previous article, we put forward negative and positive medical and social criteria for decisions concerning LST, for discussion within teams [4]. This article takes up the current debate within the SFNP concerning the establishment of guidelines, and provides support for discussions concerning the place of the ethical convictions of healthcare professionals.

The debate among professionals should include the possibility of a “conscience clause”, making it possible to ignore these guidelines in certain conditions. Our work demonstrates the real complexity of establishing universal rules to be applied to individual cases, such that the doctor can respect his or her own moral conscience. This work is supported by the other guidelines produced by French [10] and European [11] scientific societies. The Spanish Paediatric Nephrology Society advises that for each decision, the emphasis should be on individual case assessment and consideration of the best interests of the patient [11]. The French Neonatology Society has specified that it is the

responsibility of each team to decide whether or not to follow the recommendations, on a case-by-case basis [10].

Doctor-parent relationship

Our results show that the parents are not fully involved in the DMP. Most doctors (84.5%) do not wish to involve the parents in the decision. There are ethical and legal arguments in favour of greater parental involvement. The new law that came into force in April 2005 has made it obligatory to inform parents in cases of treatment limitation or withdrawal likely to put the life of the patient in danger and to record this decision in the patient's file [5].

At the ethical level, articles have been published analysing parents' feelings about their child's death some years after a LST decision was made [12]. Meyer [12] found that 55% of parents felt that they had little control over the situation in the final days of their child's life, and a quarter said that if it had been possible they would have done things differently. The Léonetti report, on end-of-life care, gave a voice to the major ideological and political currents of thought in France. It highlighted the ethical tensions between the views of healthcare professionals and patients. Professionals feel that the final decision should lie with the doctor and should be taken "with the family but never by the family", with the doctor "involving the family with tact and humanity in their course of action". Patients are demanding the right to clear appropriate information and a larger say in decision-making (including the right to refuse treatment, even if essential to their survival, and through anticipated directives) [7]."

Attitudes

One quarter of paediatric nephrologists declared that they were opposed to active attitude. They condemned voluntary intentions to accelerate death or to provoke death by the injection of a substance, as this is against the moral [13] and legal [14] codes. Passive attitude is more widely accepted because the death remains natural. Furthermore, as stated by all doctors, passive attitude is associated with fewer medical and legal consequences. Indeed, considering the issue of LST

decisions, the position in France is to make a clear distinction between a situation involving an invasive medical act that directly lead to death (active attitude) and the others situations in which a LST treatment is stopped or a new treatment is withheld (passive attitude) [15]. The active attitude is currently forbidden in France and is a criminal offence recognised as homicide by the penal code [14]. In practice, the passive attitude is tolerated because it is similar to refusing futile care: the National Ethics Consultative Committee accepted the principle of exceptional euthanasia for such cases [15]. This position, as one saw previously, was reinforced by the law of April 22, 2005 [5].

Finally, given all these concerns, it appears that a major issue is to work on the way that families perceive the situation. Due to difficulties managing the parents' and the doctors' high levels of anguish, it seems that the parents are insufficiently consulted [16]. The high level of tension implies a need for a better training and for the inclusion of neutral third party that could help in the DMP. The Léonetti report underlined the need for a training of the doctors at the same time technical (handling of the antalgic drugs in particular) but especially ethical concerning the clarification of the terms employed and the delivery of information to the families. In the United States, improvements in the training of doctors have been made by means of clinical case studies [17] and a third party religious have been chosen [12]. In France, training sessions in the paediatric nephrology departments have been proposed : the third person could be the family general practitioner [18], the treating paediatrician or a person designated by the family and known to be trustworthy [6]. The presence of a healthcare professional would have the advantage of not only assisting in the DMP but also helping the parents to deal with subsequent events.

Conclusion

This study shows how important it is for professionals to open up to parents and the SFNP on this difficult debate concerning the withdrawal of care. This opening up is particularly important at a time when one expects increasing transparency concerning decision-making and since the

publication of a French law [6] on the rights of patients in 2002 stating that patients must be included in the DMP.

Our results also demonstrate the complex nature of the DMP, given the individual nature of each case, which, in the current debate about the need to and the legality of ending lives, should incite prudence. Indeed, any approach that is too dogmatic and any definition of criteria could be inappropriate if not developed in close collaboration with the healthcare professionals concerned.

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Table 1

Q1 Have you ever decided to withdraw or to withhold life-sustaining treatment from a child in paediatric nephrology? If yes, was this decision taken in the last five years?

Q2 In your opinion, do you think it is sometimes necessary to withdraw or to withhold LST?

Q3 How important are non-scientific and scientific elements in the decision making process of deciding to withhold/withdraw treatment?

Q4 Which non-scientific and scientific elements do you feel are important?

Q5 Does fear of medical and legal complications affect your decisions?

Q6 Do you deal with treatment withdrawal and treatment withholding in the same way?

Q7 What type of information do you give to parents concerning the discussion about LST decisions?